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The Case Identification Challenge in Measuring Performance in Breast Cancer Care

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THE CASE IDENTIFICATION CHALLENGE IN MEASURING PERFORMANCE IN BREAST CANCER CARE

Major purchasers, accrediting bodies, employers, and providers are pressuring for more and better information on the quality of health services. Government agencies such as the Health Care Financing Administration (HCFA) want better information on providers' performance for purposes of monitoring the care provided with government funds, improving that care, and informing decisions on provider contracts. Major employers are seeking this information to make decisions on which insurance plans to offer their employees. Health care plans and other provider organizations want it for marketing purposes. Accrediting bodies, such as the National Committee for Quality Assurance (NCQA) and the Joint Commission on Accreditation of Healthcare Organizations (JCAHO), use performance data for accrediting purposes. Administrators want to use it to guide ongoing quality improvement within their organizations. Consumers increasingly will be provided with such information to make the informed choices central (in such basic areas as health plan coverage, provider selection, and treatment plans) to a competitive model of health services.

Health services researchers, with long-term experience in studying the quality of care, are interfacing with corporate, administrative, and provider experience in managing organizational change, as well as clinicians' experience in one-on-one patient care, to mold strategies and techniques for measuring provider performance to produce accurate information that all parties can confidently use in their decision making. While people do not find it difficult to realize the importance of valid measures of the performance of medical providers, groups, and plans, the challenges of valid performance measurement are not as easily understood. The purpose of this paper is to inform and assist cancer care providers' responses to these challenges by clarifying the issues critical to one area of performance measurement, *case identification*, and recommending possible strategies for handling these issues. The clinical context is breast cancer care, although many of the issues are pertinent to other cancers as well.

I. PERFORMANCE MEASUREMENT

Performance measurement involves both assessing the quality of the care delivered by a provider and representing that quality assessment in terms suitable for fair comparison with other providers. According to the Institute of Medicine (IOM), the quality of care is "the degree to which health services for individuals and populations increase the likelihood of desired health outcomes and are consistent with current professional knowledge."[1] To measure performance, one must collect and assess comparable information on the quality of the care delivered by specific health care providers. Performance can be measured at the level of the individual, e.g., physician, or the organization, e.g., health care plan, hospital, medical group, specialty, or geographic area. The findings are then compared to those of other individuals or groups or to a benchmark such as a goal or standard.

Obtaining comparable information across different groups is particularly challenging in today's heterogeneous and changing world of health care delivery. At this point in history, different organizations frequently use quite different information systems. Fundamental differences in the availability, reliability, and validity of data sources, in turn, make the collection of comparable data very difficult. Yet, the information must be comparable across all units for all parties – e.g., patients, providers, purchasers – to have the confidence to use the measures as bases for their decisions

Performance measures can report on the processes of care, what physicians and nurses do to patients, as well as the outcomes of the care experienced by the patient.[2,3] For example, the rate of radiation therapy among patients treated with breast conserving surgery defines a

process measure, while patient-reported well being and satisfaction are examples of outcome measures. As suggested by the definition of quality, performance measures should be supported by scientifically sound research demonstrating that better performance of the processes is associated with improved outcomes for patients with breast cancer.

II. IDENTIFYING BREAST CANCER PATIENTS

The first step in performance measurement is to identify the population of interest, i.e., the people who will constitute the denominators of the performance measures.[a] To measure performance for patients with breast cancer, as distinct from performance measures for patients undergoing breast cancer screening or follow-up to an abnormal mammogram, the population of interest will be patients with either an abnormal finding or a breast cancer diagnosis or some subset of these patients. Many measures of performance are pertinent only to newly diagnosed patients, but some measures of performance focus on recurrence or long-term outcomes, such as five year disease-free survival measure. These measures may need a study population diagnosed with breast cancer in the past.

Inclusion and exclusion criteria are used to precisely define the study population in relation to the study question. The study focus may dictate other inclusion or exclusion criteria besides the breast cancer diagnosis. For example, performance measurement regarding care to elderly Medicare patients would focus only on elderly patients within any of these populations. Samples may be limited to those for whom the diagnosis is defined as a new incident of breast cancer since standards of care may differ for patients with recurrent breast cancer. Continuous enrollment in a plan, geography, and race/ethnicity are other examples of common inclusion criteria.[4]

A case identification strategy for breast cancer measures presents two basic challenges: 1) to accurately identify *all* patients with the defining characteristics, e.g., a diagnosis of breast cancer, and 2) to identify *only* patients with these characteristics. Biases can result if the case identification strategy is only capable of identifying a convenient to gather, but nonrepresentative portion of cases.[5] For example, if the case identification strategy does better at identifying more highly educated breast cancer patients, the performance measurement results might present an inaccurate picture of the care provided if more highly educated women tended to receive better care. If the strategy is only capable of identifying patients who underwent certain procedures, e.g., those reimbursed through claims, the performance assessment would miss those who did not experience one of these procedures; a relative comparison of the care provided by two or more plans would be inaccurate if one plan provided poor care by failing to provide necessary procedures. Serious human subjects problems may result, on the other hand, if women without breast cancer are identified as cases and then contacted as if they have breast cancer.

While breast cancer care presents definite methodological challenges in all areas of performance measurement (case identification, effect and sample sizes, measure definitions, performance data collection, and risk adjustment), this paper seeks to clarify and assist with the issues inherent in case identification, i.e., accurately identifying which patients have breast cancer. Frequently multiple strategies involving different sources of data are possible, and the question becomes how best to identify the patients to study.

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[a] Performance measures have two distinct components: the denominator and the numerator. The denominator is the population of interest and all patients who were eligible to experience the particular process or outcome. The numerator is the subgroup of that population who actually did (or did not) experience the process or outcome. The data collection steps necessary to construct the denominators are distinct from those necessary to construct the numerators for the breast cancer performance measures.

Selecting the best case identification strategy primarily centers on choosing a data source for identifying the cases, but intertwined with the issue of data source are questions pertaining to the particular study population of interest and the data collection time frame. Available data sources frequently present timing constraints for case identification. These constraints become important if breast cancer measures are time sensitive, as are patient self-report measures or performance measures intended for use in ongoing quality improvement.

Performance measurement frequently relies on patient self-report of outcomes (e.g., quality of life, patient satisfaction), processes of care (e.g., preference communications, procedures), and comorbidities. Central here is the need to maximize the patient's accurate recall of the processes, outcomes, and conditions under question. The need to survey the patient within an appropriate time frame then constrains other methodological choices, including case identification ones. The data need to be collected soon after the event of interest, e.g., the breast cancer diagnosis or specific treatment, in order to minimize inaccuracy due to time delay.[6] For measures such as these, the goal is to collect these data as close to the event as possible in order to optimally preserve the reliability and validity of the patient's account.

Performance measures intended for use by providers in quality improvement activities also have demanding time frames. Feedback of information on *current* practice is critical. Accordingly, the task of identifying newly diagnosed breast cancer patients is again defined as identifying cases *as soon after diagnosis as possible.*

A number of potential strategies exist for identifying newly diagnosed patients. Possible options include using: claims or other administrative data; cancer registries; cancer registry rapid case ascertainment (RCA); pathology laboratories; physician report; and radiologists' office.

The section that follows describes these available strategies for identifying patients with newly diagnosed breast cancer. Many present serious limitations to our ability to accurately identify all new cases of breast cancer in a timely manner consistent across different health care structures and within reasonable resource constraints.

A. Using Claims or Other Administrative Data to Identify Breast Cancer Patients

Claims or administrative data usually come to mind first when thinking of sources to identify women with breast cancer. Claims codes can be searched for diagnoses of breast cancer and procedures related to breast cancer. Many, but not all, claims are submitted within four months of the patient's diagnosis. If a claim is submitted, then presumably, but not certainly, a diagnosis of breast cancer will be listed. While the use of existing administrative data is financially advantageous (i.e., costs are low because the data already exist), these data may not do an accurate job of case identification.

Claims data may not be complete. Comparison of Medicare Part A data with SEER data suggests that the hospital claims data miss a sizable proportion of breast cancer patients.[7] One study found that only 59.4 percent of SEER cases were also identified in the Medicare file. The authors attributed at least part of the missing claims data to lack of inpatient treatment, i.e., either lack of surgery or surgery in an outpatient setting.[7] Another study limited to patients treated in hospitals found that 83% of breast cancer cases identified through a central cancer registry were found in Medicare claims data.[8]

Not all cases identified by diagnostic and procedure codes in claims data are valid breast cancer diagnoses, moreover. Using medical record data to evaluate a claims-based algorithm for identifying breast cancer patients in an HMO setting, one study found that 17% of the

patients identified through the claims data were incorrectly identified due to coding errors, diagnostic errors, and upcoding. One half of those incorrectly identified involved negative biopsies. This study did not evaluate the number of breast cancer patients not identified by the claims data.[9]

While claims data have been successfully used in fee-for-service settings,[10] there are limitations to using administrative data across multiple settings. Some health maintenance organization (HMO) settings do not have claims data or other data that record each service rendered to an enrollee. Claims data may be limited to services which the HMO contracts to specialist providers or hospitals. Where claims data are absent, women with breast cancer will either not be included in the sample or strategies will need to be implemented to identify these women from a different data source.

While not submitting claims, some health plan organizations may be able to use their administrative data to generate breast cancer patient lists. For such a strategy to generate a complete (unbiased) sampling frame, plans not only will have to have centralized, automated data systems which contain records of all individual enrollees including the name, gender, diagnosis, and date of services for this diagnosis with a unique identifier (e.g., a social security number), but they also will need to be organized so that identifying patients within four months of diagnosis is feasible. The case identification data will need to be verified, using a separate source such as registry data. This method has more potential when the population of interest are the members of one or a few plans. It is not applicable across fee-for-service settings and this is problematic when the population of interest is geographically defined.

B. Using Cancer Registries to Identify Breast Cancer

Cancer registries, which collect and disseminate information on cancer cases, provide an important data source for case identification not available to researchers in many other disease areas. But registries are not necessarily a panacea for case identification. Much depends on the needs of the research with respect to the institutional and geographic definition of the population and the timeliness of the data collection in relationship to the date of diagnosis.

There are different levels of tumor registry systems with different speeds of reporting and different purposes. Many hospitals maintain registries on cancer patients under their care, either for American College of Surgeons certification or to meet state or federal requirements. Population-based registries focus on all cancer cases within a specified geographic area. Some areas have regional-level registries. Some states aggregate information on cancer patients throughout the state into state-level registries. While hospital registries are oriented towards administrative and patient care purposes,[11] regional and state-level population-based registries are oriented towards research and planning.[12] Some focus on incidence determination as their primary goal; others are oriented towards epidemiological research or cancer control.[13] The type of data collected and the procedures used vary accordingly. For example, as part of their administrative and patient care orientation, many hospital registries report breast cancer recurrence, while most other registries do not.

While many hospitals have a cancer registry, hospital registries cannot be solely relied upon for case identification due to the increasing proportion of both diagnosis and treatment in the ambulatory setting.[14] Additionally, use of hospital registries for case identification would mean decentralized data collection. The operational scope of this task for a research team would be major, given that any one site is likely to have a substantial number of hospitals diagnosing breast cancer. To give an idea, the American Hospital Association (AHA) Guide to the Health Care Field lists 39 hospitals in Maricopa County in Arizona, 14 of which have cancer programs approved by the American College of Surgeons.[15] Thirty-seven hospitals are listed for Dade County, Florida, 8 of which have cancer programs approved by the American College of

Surgeons.[15] After the hospitals with registries are identified, each individual hospitals would need to be contacted to learn more about the registry data elements available in the post-diagnosis time period. Multiple human subjects committee approvals probably would be required. Additionally, researchers would need to be sensitive to the possibility that working directly with individual hospital registries might be viewed by regional or state registries as end-running, interfering with, or delaying their operations.

Central registries, by definition, reduce the degree of decentralization and the case identification problems related to decentralization. Not all central registries are population-based, however. Reporting may be on a voluntary basis and some institutions may choose not to report cases to the registry. A research team in Virginia, for example had to confront the fact that only about 50 hospitals, representing 85% of hospital beds in Virginia, reported cases to the Virginia Cancer Registry.[8]

Population-based registries, by definition, have the advantage of inclusiveness. A study of the hospital cancer case reporting in six SEER areas found a 97% completeness rate.[16] They have been successfully used for population-wide research,[17] since reporting of all cases, regardless of health care setting, is required. While registry data can be used to identify breast cancer patients across multiple settings within a geographic area, additional sources must be used to identify specific HMO plan or type of fee-for-service coverage. Thus, one project comparing breast cancer survival and treatment in patients in two specific HMOs and fee-for-service relied substantially on registry data for survival and treatment information but requested patient lists directly from the two HMOs and Medicare claims files.[18]

Reporting requirements are not uniform among registries, although there is an increasing focus on standardized or common data items.[19] Many hospital registries report to standards of the College of Surgeons Commission on Cancer, while many central registries use American Association of Central Registries data requirements; the National Cancer Institute has specified SEER data requirements.[19]

The Surveillance, Epidemiology, and End Results (SEER) Program, a project of the National Cancer Institute (NCI) collects cancer data from population-based cancer registries in fourteen locations in the United States. The areas covered by these SEER registries represent approximately 14% of the U.S. population and include Connecticut, Atlanta, rural Georgia, Detroit, Iowa, Arizona, Hawaii, Los Angeles, New Mexico, San Francisco-Oakland, San Jose-Monterey, Seattle-Puget Sound, and Utah.[20] All SEER registries have similar reporting requirements, and the data are subject to verification procedures both at NCI and at each registry.[21]

As a general rule, one cannot rely on the registry data from SEER or central registry normal reporting systems for timely information on incident cases within the immediate post-diagnosis time period. SEER data, for example, may have up to a two-year time lag.[7] It appears reasonable to expect that many states' registry data similarly may not be available until one to two years after the diagnosis. While this limits the utility of registry data for prospective studies, retrospective studies of breast cancer care have been able to utilize central registry data for case identification.[22]

C. Using Cancer Registry Rapid Case Ascertainment (RCA) Reporting

Some registries additionally have rapid case ascertainment (RCA) systems which collect selected subsets of registry data much earlier than is otherwise the case. Rapid case ascertainment means that the registry reviews pathology reports directly to obtain data on cases, rather than waiting for hospitals to report the full scope of information on cases. Case identification data are thereby collected within the first months after diagnosis. Registries with

rapid case ascertainment (RCA) reporting are thus a promising source of early case identification data.

The Cancer Surveillance Program (CSP) of Los Angeles County, for example, will conduct RCA review of pathology reports at a per-case charge to the investigator. Every pathology report which appears possibly reportable is photocopied. CSP staff also will collect additional demographic information from the hospital's computer system or admitting face sheet. Since RCA review is performed monthly, the data are available to the researcher within 4 months of diagnosis, on average.[23] As another example, the North Carolina Central Cancer Registry has implemented a RCA system which ascertains cases for the Carolina Breast Cancer Study within two weeks to one month after diagnosis. This system relies primarily on the hospital registrars for the rapid reporting.[24]

In sites without formal RCA systems, it may be possible to obtain registry cooperation in reporting similar data quickly. Many registries may have the capability to implement RCA procedures to report data elements within four months post-diagnosis, given the necessary resources.

The specific data items collected through RCA reporting may vary, but many include limited demographic information as well as information identifying the patient and the physician who requested the pathology report. These data are sufficient for identifying new breast cancer patients and linking registry data to other data files, but they do not include information on stage at diagnosis nor treatment. The fact that stage at diagnosis is not assigned as part of the rapid reporting means that any prospective study cannot be restricted to selected stages without first getting additional information (i.e., contacting the patient's physician or reviewing pathology or medical record data) to obtain the information about each patient's stage. Many RCA systems do not routinely include the patient's phone number, but may be willing to negotiate collecting it. If not, the phone number will have to be obtained from the physician's office if data are to be obtained by surveying the patient by telephone.

D. Using Pathology Laboratories, Physician Report, or Radiologists' Offices to Identify Breast Cancer Patients

In addition to claims and registry data, a number of decentralized approaches are available for consideration. One possible source of case identification data is pathology reports. Research staff in one study reviewed pathology reports at five hospitals on a regular basis for over three years to identify breast cancer patients. They were able to conduct phone interviews with these patients by 4.5 months, on average, after the definitive surgery.[25] Since pathology data form the basis for cancer diagnoses in the first place and are the original source of data for all registries, this route is going directly to the source. Most pathology reports will contain the patient's name, date of birth, physician name, diagnosis, and state, in addition to the pathology information used for staging. While some reports will contain a stage designation, the pathology data in the reports can be used to assign stage to all patients utilizing a validated algorithm.

Similar to using hospital registries, this method represents an extremely decentralized approach to case identification. There are around 36-40 free standing pathology laboratories in Arizona for example, including about 25 free standing laboratories in Maricopa County (Phoenix).[26] To access data from these pathology laboratories, the Human Subjects Protection Committee requirements governing *each* laboratory and hospital would have to be researched and met. Researchers would need to recruit and negotiate arrangements for selecting and receiving pathology report copies at the level of the individual laboratory. Again, researchers would need to be sensitive to potential physician, hospital, and registry concerns that the research field operations not interfere with or delay the established reporting protocols.

An alternative approach might be to collect case identification information directly from the diagnosing physician. The physician might be asked to complete and submit a one-page form at the time the pathology report was received with the breast cancer diagnosis. This approach shares with the pathology laboratory strategy the advantage of going directly to the source. The form could include an item asking for the stage at diagnosis since the physician makes a determination of stage at this point

On the down side, this approach shifts a considerable portion of the burden directly to the physician. One consequence is likely to be difficulty securing physician compliance in completing and submitting forms. This consequence would threaten the completeness of the case identification data, a critical problem for any performance measurement project.

A somewhat different source of case identification data could be mammography reports. Mammography reports identify persons with abnormal mammography findings. Breast cancer cases would then need to be identified from among the patients with abnormal mammograms.[b] Use of mammography reports would allow identification of two additional patient cohorts, those with no abnormality noted on mammogram, and those with a possible abnormality or indication on the mammogram of the need for further diagnostic studies, which would facilitate performance measurement in the areas of screening and diagnostic care in addition to breast cancer care.

This method of case identification represents an extremely decentralized approach to case identification, similar to the methods of going to hospital registries or pathology laboratories. There are at least two additional problems with this approach. First, only about one in one hundred women receiving a mammogram will have breast cancer. So clearly the strategy will be cost effective only if the data about the women who constitute the denominator (i.e. all women who receive mammograms) will contribute data relevant to additional analyses. A second problem is that approximately 10% of elderly women are diagnosed with breast cancer in the setting of a normal mammogram. The proposed strategy would not identify these cases unless the women with normal mammograms were identified by another mechanism.

IIII. RELATED CHALLENGES

An additional challenge of case identification is securing necessary approvals to access these data for purposes of assessing performance measurement. Working with any of these case identification strategies will involve review by at least one Human Subjects Protection Committee. The amount of time it will take for them to consider and approve a project related to performance measurement may be substantial. HSPC approval for case identification, when the case identification is to be used to survey patients, involves close attention to issues of informed patient consent and physician contact.

Physician contact involves contacting the office of the physician who performed the biopsy, as identified to registry staff by the pathology report. The reasons for this contact may vary. Some registries, for example, want the physician notified that researchers intend to contact the patient and informed of the purposes of the study.[23] Some registries require the physician's

[b] Collecting case identification data in the radiologist's office also offers the opportunity to collect baseline quality of care and functional status data from all women having mammograms. While not germane to case identification per se, a serious problem for outcome measurement is the lack of a pre-morbid (i.e., pre breast cancer) set of data about baseline function, quality of life, and comorbidity. Defining the study population according to those receiving mammogram screening would allow patient survey at the time of mammography and allow collection of pre-morbid data (as well as allow the opportunity to measure follow-up to mammograms as an additional measure).

active approval to contact the patient; others require that the physician be allowed time to deny approval. Physician involvement allows an exclusion screen where physician input advises against contacting a patient who might be harmed by such contact, e.g., a patient with severe psychiatric health problems. In some cases, it is necessary to request specific information (e.g., the patient's phone number if not obtained from the original case identification source) or assistance in verifying some aspect of the case (e.g., new versus recurrent) or confirmation that the patient was indeed under the care of that physician. In some sites, the registry itself may want to contact the physician first.[27] Some RCA groups also require that registry staff first contact the patient to ask permission to release her name.[28] The timing, efficacy, and cost of these additional services needs to be considered in planning a case identification strategy.

IV. STRATEGY CHOICE

Table 1 summarizes the relative advantages and disadvantages of the different strategies. Clearly, most of the approaches involve some serious limitations to obtaining valid and comparable data across multiple settings. In particular, claims data are limited with respect to the accuracy of the case identification, regular registry data with respect to the timeliness of the case identification, registry RCA data with respect to the added cost of rapid case ascertainment, pathology and radiology data with respect to the staff resources needed for primary data collection, and physician report with respect to staff resources and physician burden. The scientific implications of the limitations in the accuracy or timeliness of case identification make the claims and regular registry strategies unacceptable for case identification when patient self-report data is to be collected soon after diagnosis. The RCA approach appears to have the least limitations. The RCA strategy relies heavily on the cooperation and capabilities of registries, while the pathology report strategy relies heavily on the pathology laboratory personnel, the physician report on physicians and their office staff, and the mammogram on radiology services personnel. Moreover, the latter three approaches represent new primary data collection efforts. As such, they pose major operational challenges to a project, most particularly in the areas of gaining cooperation from decentralized laboratories and physicians' offices and closely monitoring the ongoing data collection efforts. The RCA approach, on the other hand, relies on an existing data collection system with familiar requirements and monitoring procedures already in place. It reimburses registry and hospital staff for their work to supply the data needed, rather than burdening laboratory personnel or physicians. Utilizing an existing data collection system staffed by skilled data collectors and managers will result in substantially better data in terms of accuracy, response rate, and completeness. For these operational reasons, the RCA strategy appears preferable to the pathology laboratory, physician report, or radiology services strategy.

Further research is needed on the possibilities for implementing this strategy in the various registry systems throughout the United States and on the validity and reliability of case identification data so obtained. Currently, registry cooperation in rapidly ascertaining cases would need to be pursued on a site by site basis. Important preliminary steps would include detailed discussions with registry officials to identify and negotiate the possibility for rapid case ascertainment of data; verification that the registry is not restricting access to eligible breast cancer patients because patients have already been committed to other research projects; verification that data are accessible on cases diagnosed in outpatient settings; investigation of the cost of collecting data through the registry; and investigation of the procedural, financial, and human subjects protection committee requirements of all sources of case identification and performance data.

A strategy that relies on a data source that varies from site to site is usually neither optimal nor sufficient in the long run. Registry officials and the government agencies that provide their support should be encouraged to adopt quality of care analyses as a primary purpose of the

registry system. Since much quality of care analysis today relies on patient self-report, all registries will need to enhance their capacity to *rapidly* ascertain cases and collect the appropriate identifying information needed for patient contact. More rapid verification of stage at diagnosis is also needed.

Case identification is an important and complex undertaking. An easy or standardized approach for identifying breast cancer cases for performance measurement has not yet been worked out, but registry rapid case ascertainment has considerable potential for accurately producing the information needed. Performance measurement researchers would be well-advised to work closely with cancer registry officials to realize this potential. Improving the understanding of critical steps in case identification across health services research, clinical settings, pathology laboratories, registries, and hospital management is likely to generate more valid data at lower costs, data which can be used with confidence to assess and improve care delivered to patients with breast cancer.

Table 1: COMPARISON OF DIFFERENT STRATEGIES FOR CASE IDENTIFICATION

	Claims Data	State-level or SEER Registry Data	Hospital Registry Data	Registry Rapid Case Ascertainment Data	Pathology Lab Data	Clinician Report	Radiology Service Data
Data Accuracy							
• Inclusive of all incident cases	No	Yes	No	Yes	Yes	Yes	Yes
• covers ambulatory diagnoses	Yes	Yes	No	Yes	Yes	Yes	Yes
• covers all managed care settings	No	Yes	Yes	Yes	Yes	Yes	Yes
• data likely to be complete	No	Yes	Maybe	Yes	Maybe	No	No
• Exclusive of all non cases (e.g., incisional biopsies without a cancer diagnosis)	No	Yes	Yes	Yes	Yes	Yes	Yes[c]
• Case ID data verified through review	No	Yes	Yes	Probably Yes	Yes	Clinician Data	No
Timeliness							
• Available within four months of diagnosis or could be, with added resources	Possibly	No	Possibly	Yes	Yes	Usually	Yes
Burden							
• Little direct burden on patient's clinician	Good	Good	Good	Case Verification Needed	Good	Major Burden	Good
• Little burden on clinician's office	Good	Good	Good	Case Verification Needed	Address and Phone # Needed	Major Burden	Address and Phone # Needed
Project Resources							
• Primary data collection effort not needed	Good	Good	Varies by centralized	Good	Varies by centralized	Primary Data Collection Needed	Varies by centralized
• Human Subjects Protection clearance likely to be centralized and clear cut	Good	Good	No	Good	No	No	No
• Data do not need to be purchased	Good			Budget Needed	Budget Needed	Good	Budget Likely Needed
Data Available							
• To ascertain stage at diagnosis	No	Yes	Yes	Yes	Yes	Yes	Yes[c]
• To ascertain stage within four months of diagnosis	No	No	Unlikely	No	Yes	Yes	Yes[c]
• To contact patient by phone		Yes		Yes, if negotiated	No	Yes	Yes
• To contact patient by mail	Yes	Yes		Yes, if negotiated	No	Yes	Yes
• On some patient demographics	Yes	Yes		Yes, if negotiated		Yes	
Special Performance Data Available							
• On mammogram follow-up	Yes	No	No	No	No	No	Could Be Added
• On recurrence for 5-year disease free survival measure	No	No	Yes	No	No	No	No

Note: Shading indicates most serious limitations.

[c] When pathology data also consulted.

REFERENCES

[1] Lohr KN (ed.) Medicare: A Strategy for Quality Assurance. Committee to Design a Strategy for Quality Review and Assurance in Medicare, Institute of Medicine, Division of Health Care Services. Washington, DC: National Academy Press, 1990.

[2] Donabedian A. Promoting quality through evaluating the process of patient care. *Med Care* 1968;6:181-202.

[3] Donabedian A. The Definition of Quality and Approaches to Its Assessment. Ann Arbor, Michigan: Health Administration Press, 1980.

[4] HEDIS 3.0. Health Plan Employer Data and Information Set. National Committee for Quality Assurance (NCQA), 1997.

[5] Heckman J. Sample selection bias as a specification error. *Econometrica* 1979;47:153-161.

[6] Abelson RP, Loftus EF, Greenwald AG. Attempts to improve the accuracy of self-reports of voting. In Tanus JM (ed.) Questions about Questions: Inquiries into the Cognitive Bases and Surveys. New York, NY: Russell Sage Foundation, 1991.

[7] Warren JL, Riley GAF, McBean AM, Hakim R. Use of Medicare data to identify incident breast cancer cases. *Health Care Financing Review* 1996;18(1):237-246.

[8] McClish DK, Penberthy L, Whittemore M, Newschaffer C, Woolard D, Desch CE, Retchin S. Ability of Medicare claims data and cancer registries to identify cancer cases and treatment. *Am J Epidemiol* 1997;145(3):227-233.

[9] Solin LJ, MacPherson S, Schultz DJ, Hanchak NA. Evaluation of an algorithm to identify women with carinoma of the breast. *J Medical Systems* 1997;21(3):189-199.

[10] Hillner BE, MacDonald MK, Penberthy L, Desch CE, Smith TJ, Maddux P, Glasheen WP, Retchin SM. Measuring standards of care for early breast cancer in an insured population. *J Clin Oncol 1997*;15(4):1401-1408.

[11] Young JL. Chapter 13. The hospital-based cancer registry. In Jensen OM, Parkin DM, Maclennan R, Muir CS, Skeet RG (eds.) *Cancer Registration Principles and Methods*. Lyon, France: International Agency for Research on Cancer, 1991, pages 177-184.

[12] Jensen OM, Storm HH. Chapter 3. Purposes and uses of cancer registration. In Jensen OM, Parkin DM, Maclennan R, Muir CS, Skeet RG (eds.) *Cancer Registration Principles and Methods*. Lyon, France: International Agency for Research on Cancer, 1991, pages 7-21.

[13] Austin DF. Types of registries: Goals and objectives. In Menck H and Smart C (eds.) *Central Cancer Registries: Design, Management, and Use*. Hardwood Academic Publishers. 1994, pages 1-12.

[14] Warren JL, Riley GF, Potosky AL, Klabunde CN, Richter E, Ballard-Barbash R. Trends and outcomes of outpatient mastectomy in elderly women. *J Natl Cancer Inst* 1998;90(11):833-840.

[15] AHA Guide to the Health Care Field, 1997-98 edition. Chicago, IL: American Hospital Association, 1997.

[16] Zippin C, Lum D, Hankey BF. Completeness of hospital cancer case reporting from the SEER program of the National Cancer Institute. *Cancer* 1995;76:2343-2350.

[17] Stockton D, Davies T, Day N, McCann J. Retrospective study of reasons for improved survival in patients with breast cancer in East Anglia: Earlier diagnosis or better treatment? *BMJ* 1997;314:472-475.

[18] Potosky AL, Merrill RM, Riley GF, Taplin SH, Barlow W, Fireman BH, Ballard-Barbash R. Breast cancer survival and treatment in health maintenance organization and fee-for-service settings. *J Natl Cancer Inst* 1997;89(22):1683-1691.

[19] Gordon B. Data set planning. In Menck H and Smart C (eds.) Central Cancer Registries. Design, Management, and Use. USA: Harwood Academic Publishers, 1994.

[20] National Cancer Institute. SEER Incidence Data Dictionary and Population Documentation. http://www-seer.ims.nci.nih.gov.

[21] National Cancer Institute. About SEER. http://www-seer.ims.nci.nih.gov/AboutSEER.html.

[22] Ma M, Bell J, Campbell S, Basnett I, Pollock A, Taylor I. Breast cancer management: Is volume related to quality? *Br J Cancer* 1997;75(11):1652-1659.

[23] USC School of Medicine. Cancer Surveillance Program Procedure Guide, 1996.

[24] Aldrich TE, Vann D, Moorman PG, Newman B. Rapid reporting of cancer incidence in a population-based study of breast cancer: One constructive use of a central cancer registry. *Breast Cancer Research and Treatment* 1995;35:61-64.

[25] Silliman RA, Troyan SL, Guadagnoli E, Kaplan SH, Greenfield S. The impact of age, marital status, and physician-patient interactions on the care of older women with breast carcinoma. *Cancer* 1997;80:1326-1334.

[26] Personal communication with Georgia Yee, CTR Program Manager, Arizona Department of Health Services, Arizona Cancer Registry, August 4, 1997.

[27] Minnesota Department of Health. Adopted permanent rules relating to cancer surveillance system. Minnesota Rules: Chapter 4606, August 7, 1997.

[28] Personal e-mail communication with Sally Bushhouse, Director of the Minnesota Department of Health's Chronic Disease & Environmental Epidemiology Department, August 7, 1997.

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